



Overview

Points To Remember About Systemic Lupus Erythematosus (Lupus)

- Lupus can affect many body parts, including the joints, skin, kidneys, heart, lungs, blood vessels, or brain.
- You will have periods of illness (flares) and wellness.
- Anyone can get lupus, but it most often affects women. Lupus is also more common among African American, Hispanic, Asian, and Native American women.
- Genes play an important role in lupus, but other factors are also involved.
- Most people will see a rheumatologist for their lupus treatment. Treatment generally consists of a team approach.
- Learning to recognize the warning signs of a flare can help with reducing or preventing the flares.

Systemic lupus erythematosus (lupus) is a disease that can damage many parts of the body, such as the joints, skin, kidneys, heart, lungs, blood vessels, and brain. You can't catch lupus from another person.

If you have lupus you will have periods of illness (flares) and periods of wellness (remission).

What happens in lupus?

Lupus occurs when the immune system, which normally helps protect the body from infection and disease, attacks different parts of the body.

Who Gets

We know that many more women than men have systemic lupus erythematosus (lupus). Lupus is more common in African American women than in Caucasian women and is also more common in women of Hispanic, Asian, and Native American descent. African American and Hispanic women are also more likely to have active disease and serious organ system involvement. In addition, lupus can run in families, but the risk that a child or a brother or sister of a patient will also have lupus is still quite low.

Although SLE usually first affects people between the ages of 15 and 45 years, it can occur in childhood or later in life as well.

Symptoms

Each person with systemic lupus erythematosus (lupus) has slightly different symptoms that can range from mild to severe. You may have symptoms in only one or in many parts of your body. Symptoms may also come and go over time.

Some of the most common symptoms of lupus include:

- Painful or swollen joints (arthritis).
- Unexplained fever.
- Extreme fatigue.
- Red rashes, most often on the face.
- Chest pain upon deep breathing.
- Hair loss.
- Sensitivity to the sun.
- Mouth sores.
- Pale or purple fingers and toes from cold and stress.
- Swollen glands.
- Swelling in the legs or around the eyes.

Other symptoms could include:

- Anemia (a decrease in red blood cells).
- Kidney inflammation, which typically requires drug treatment to prevent permanent damage.
- Headaches, dizziness, depression, confusion, or seizures if the disease affects the central nervous system.
- Inflammation of the blood vessels.
- Decreased number of white blood cells or platelets.
- Increased risk of blood clots.
- Inflammation of the heart or the lining that surrounds it.

- Heart valve damage.

Causes

No one completely understands what causes systemic lupus erythematosus (lupus). Studies suggest that a number of different genes may determine your risk for developing the disease.

Some environmental factors also appear to play a role in lupus. In particular, scientists are studying the effects of sunlight, stress, hormones, cigarette smoke, certain drugs, and viruses.

Diagnosis

Diagnosing systemic lupus erythematosus (lupus) can be difficult and may take months or even years. Although there is no single test for lupus, your doctor may do the following to diagnosis you with the condition:

- Ask you about your medical history.
- Give you a physical exam.
- Take samples of blood, skin, kidney, or urine for laboratory tests. The most useful tests look for certain antibodies in the blood.

Treatment

Treatments for systemic lupus erythematosus (lupus) have improved dramatically in recent decades, giving doctors more choices in how to manage the disease. Because some treatments may cause harmful side effects, you should immediately report any new symptoms to your doctor. You should also talk to your doctor before stopping or changing treatments.

Treatments for lupus include:

- **Medications:**
 - **Nonsteroidal anti-inflammatory drugs (NSAIDs)** are used to treat joint or chest pain or fever. Ibuprofen and naproxen sodium are available over the counter, whereas other NSAIDS are available by prescription only.
 - **Antimalarials** prevent and treat malaria, but doctors have found that they also are useful for treating fatigue, joint pain, skin rashes, and inflammation of the lungs caused by lupus. These drugs may also prevent flares from recurring.
 - **Corticosteroids**, strong inflammation-fighting drugs, may be taken by mouth, in creams applied to the skin, by injection, or by intravenous (IV) infusion (dripping the drug into the vein through a small tube). Because they are potent drugs, your doctor will seek the lowest dose required to achieve the desired benefit.

- **Immunosuppressives** restrain an overactive immune system and may be prescribed if your kidneys or central nervous systems are affected by lupus. These drugs may be given by mouth or by IV infusion. The risk for side effects increases with the length of treatment.
- **B-lymphocyte stimulator (BlyS)-specific inhibitors** reduce the number of abnormal B cells thought to be a problem in lupus.
- **Alternative and complementary therapies** may improve symptoms, although research has not shown whether they help treat the disease. Examples include:
 - Special diets.
 - Nutritional supplements.
 - Fish oils.
 - Ointments and creams.
 - Chiropractic treatment.
 - Homeopathy.

In many cases you may need to take medications to treat problems related to lupus, such as high cholesterol, high blood pressure, or infection.

Who Treats

Most people will see a rheumatologist for their systemic lupus erythematosus (lupus) treatment. A rheumatologist is a doctor who specializes in rheumatic diseases (arthritis and other inflammatory disorders, often involving the immune system). Clinical immunologists (doctors specializing in immune system disorders) may also treat people with lupus. As treatment progresses, other professionals often help, including:

- Primary care doctors, such as a family physician or internal medicine specialist, who coordinates care between the different health providers and treats other problems as they arise.
- Mental health professionals, who help people cope with difficulties in the home and workplace that may result from their medical conditions.
- Nephrologists, who treat kidney disease.
- Cardiologists, who specialize in the heart and blood vessels.
- Hematologists, who specialize in blood disorders.
- Endocrinologists, who treat problems related to the glands and hormones.
- Dermatologists, who treat skin problems.

Living With It

Dealing with a long-lasting disease like systemic lupus erythematosus (lupus) can be hard on the emotions. You might think that your friends, family, and coworkers do not understand how you feel. Sadness and anger are common reactions.

Besides working with your doctor to determine a treatment plan, there are a few things you can do to help you live with lupus:

- Learn to recognize the warning signs of a flare so that you and your doctor might reduce or prevent them. These warning signs include:
 - Increased tiredness.
 - Pain.
 - Rash.
 - Fever.
 - Stomach discomfort.
 - Headache.
 - Dizziness.
- Eat a proper diet, exercise, and learn relaxation techniques to help cope with stress. A healthy lifestyle, as well as quitting smoking, will also reduce your risk for heart disease associated with lupus. Talk to your doctor before starting an exercise program.
- Develop and maintain a good support system of family, friends, medical professionals, community organizations, and support groups.

Pregnancy and Contraception for Women With Lupus

Although pregnancy in women with lupus is considered high risk, most women with mild to moderate lupus can have healthy pregnancies. Regular care and good nutrition during pregnancy are essential. Talk to your doctor if you are pregnant or plan to become pregnant.

Research shows that birth control pills do not increase the risk for severe flares among women with lupus. As a result, doctors are increasingly prescribing oral contraceptives to women with inactive or stable disease.

Research Progress

Recent research on systemic lupus erythematosus (lupus) has focused on:

- **Genetics:** A number of genes associated with lupus risk and severity have been discovered.
- **Sex differences:** Researchers are trying to understand the biological bases for sex differences in immune and inflammatory systems to better understand why are women more likely than men to have the disease.
- **Biomarkers** such as certain proteins or genes could help doctors predict flares in lupus.
- **Disease processes:** researchers are exploring possible triggers for lupus. Examples include:
 - Biofilms, or protective coatings that surround some bacteria.
 - TREML4, a protein found on certain immune cells.
 - Viruses.
 - Hormones.
- **Treatment:** Scientists are exploring how lupus develops and how therapies impact the

course of the disease. They are also exploring drugs to prevent or delay kidney failure, one of the most serious and life-threatening complications of lupus.

Experts are also collaborating to develop registries and working groups, such as:

- Lupus Registry and Repository, which gathers medical information, as well as blood and tissue samples from patients and their relatives. This will help identify genes that make someone more at risk for the disease.
- A registry to collect information and blood samples from children affected by neonatal lupus, as well as their mothers. This will help improve diagnosis, prevention, and treatment of lupus.
- Lupus Federal Working Group, which gathers experts across various public health agencies, pharmaceutical companies, and professional organizations.
- National Institutes of Health (NIH) Accelerating Medicines Partnership, which aims to reduce the time and cost of developing new diagnostics and therapies for diseases, including lupus.

Related Resources

U.S. Food and Drug Administration

Toll free: 888-INFO-FDA (888-463-6332)

Website: <https://www.fda.gov>

[Drugs@FDA](https://www.accessdata.fda.gov/scripts/cder/daf) at <https://www.accessdata.fda.gov/scripts/cder/daf> [Drugs@FDA](https://www.accessdata.fda.gov/scripts/cder/daf) is a searchable catalog of FDA-approved drug products.

Centers for Disease Control and Prevention, National Center for Health Statistics

Website: <https://www.cdc.gov/nchs>

American College of Rheumatology

Website: <https://www.rheumatology.org>

American Autoimmune Related Diseases Association, Inc.

Website: <https://www.aarda.org>

Arthritis Foundation

Website: <https://www.arthritis.org>

Lupus Clinical Trials Consortium, Inc.

Website: <https://www.lupusclinicaltrials.org>

Lupus Foundation of America

Website: <https://www.lupus.org>

Lupus Research Alliance

Website: <http://www.lupusresearch.org>

SLE Lupus Foundation

Website: <https://www.lupusny.org>

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- [Asian Language Health Information](#)
- [Spanish Language Health Information](#)

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Related Information

[Lupus, Lo que las personas con lupus deben saber sobre la osteoporosis](#)
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[Lupus, Easy-to-Read Fast Facts](#)
[Lupus, Living With: Health Information Basics for You and Your Family](#)
[Lupus, What People With Lupus Need to Know About Osteoporosis](#)
[Systemic Lupus Erythematosus, Handout on Health](#)